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ABSTRACT

This paper reports on the development of a set of four family outcomes concerned with the measurement of child growth and development as part of a 5-year project by the Early Childhood Research Institute on Measuring Growth and Development to develop a comprehensive assessment model for young children, birth to age 8, with disabilities. It first lists 11 family outcomes identified as a result of interviews with parents of children with disabilities. It then explains the four outcomes selected to be part of the model: (1) families will have a basic understanding of child development and will be able to identify needs for their child, including those related to cultural, linguistic or disability specific issues; (2) families will be able to assess how their child's development is progressing related to general outcomes identified on the Individualized Education Program/Individual Family Service Plan; (3) families will be confident in their abilities to make choices about interventions for their child and will be able to implement those interventions effectively; and (4) families will feel that their beliefs and values are respected by other members of their child's team and will see themselves as equal and integral members. Future research plans include validation of the four outcomes and selection of additional outcomes. (DB)

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MEASURING GROWTH & DEVELOPMENT

TECHNICAL REPORT #7

FAMILY OUTCOMES IN A GROWTH AND DEVELOPMENTAL MODEL

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APRIL 1998

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Introduction

The passage of the Education for All Handicapped Children's Act in 1975 was brought about in large part by parents of children with disabilities and their families. While PL 94-142 did not require that goals be written specifically for family outcomes, it did outline the requirements for each child's Individualized Education Plan (IEP) and required extensive family involvement and input in the design and evaluation of the IEP. With the passage of PL 99-457 in 1986, the federal government provided incentives in each state to develop Individualized Family Service plans (IFSPs) for each family. Both the spirit and intent of this legislation was to provide a mechanism for professionals and families to work *together* to meet the individual needs of a child.

Beyond the legal imperative, a primary reason for working collaboratively with families is that the child should be seen as part of a larger "system" — his or her family. Roberts (1990) has pointed out that by viewing each child in the context of her family, professionals must consider each family's personal style and culture pattern. These, in turn, will influence the needs and expectations that families have for their children. Recently, Bailey, McWilliam, Darkes, Hebeler, Simeonsson, Spiker, and Wagner (1998) presented a discussion about desired family outcomes and strategies for documenting their attainment. The authors make a strong case for assessing *family outcomes* as part of a comprehensive early intervention program.

McWilliam, Winton, and Crais (1997) have identified a number of questions that professionals should ask themselves as they evaluate their work with a family. First, *what do families want?* It is important to determine what priorities a family has for a child's education plan. Does the family want you to find a "solution" to a problem or do they wish to be a part of the assessment and intervention process? Does a family identify needs that are outside of a professional's particular expertise, and if so, is she or he prepared to assist the family in accessing other resources?

A second question is, *how are family needs related to family values and cultural expectations* can be answered only by working closely with a family. Lynch and Hanson (1992) have identified a number of steps that a professional can take in order to become more culturally competent and thus have a greater understanding about the diverse family values and cultural expectations. These include (a) becoming aware of the cultural groups represented in the communities that you serve; (b) working with interpreters to fully understand family concerns and priorities; (c) accepting various levels of family involvement; and (d) using a variety of methods for obtaining family information including surveys, interviews, and questionnaires.

Finally, professionals must address this question: *How can I build a positive and collaborative relationship with families.* McWilliam, Winton, and Crais (1997) have pointed out that the role of the professional is not to assess or evaluate families. In fact, professionals and families must work together to make joint decisions about a child's education program.

Family Outcomes

Professionals generally understand, or at least accept, their responsibility to assess *child outcomes*. However, rarely are *family outcomes* considered or, much less, assessed. What are family outcomes? How do they vary from family to family? How can we measure them? In order to emphasize outcomes for families, as well as children, as a part of our Comprehensive Assessment Model, we subcontracted with PACER, Inc. to oversee the development of family outcomes as part of the Institute research activities. As a first step, PACER conducted a series of interviews with parents of children with disabilities to determine what they perceive as important family outcomes. The families identified the following:

- Families will understand the law as it pertains to the IFSP/IEP Process.
- Families will understand basic child development and be able to assess how their child's development is progressing.
- Families will understand their child's disability and know how to access supports within the community related to that disability.
- Families will be able to identify their needs, including those related to cultural, linguistic, or disability specific issues.
- Families will be made aware of the /IEP system as soon as a need is identified and will have information on how to access those services if desired.
- Families and children will receive services they have identified as being necessary. These services will be made available in a timely manner.
- Families will perceive themselves as equal and integral members of the team.
- Families will be confident in their abilities to make choices about services for their child with a disability.
- Families will be self-advocates.
- Families will understand the differences between the IFSP and the IEP processes and the resulting implications for service provision.
- Families will feel that their beliefs and values are respected by other members of the team.

While each of these are important family outcomes, we are interested in the family outcomes that relate specifically to a families involvement in their child's growth and development over time. Thus, as a second step, ECRI-MGD Investigators, PACER staff, and the ECRI-MGD Professional Advisory Board discussed the general family outcomes that resulted from the family interviews. Four outcomes that relate specifically to our primary focus of measuring child growth and development were selected from the list. Finally, we incorporated each of these four family outcomes into our Comprehensive Assessment Model (see attached Figure). A brief discussion of each of these outcomes and ways to assess them are discussed below.

Family Outcomes in a Growth and Development Model

Identifying and Measuring Family Outcomes.

Clearly, potential family outcomes may range from a family's overall satisfaction with early intervention services to a families active participation in intervention planning. For purposes of this project, our focus is on the identification and measurement of family outcomes that relate specifically to a child's growth and development. Working collaboratively with PACER Center, we have identified a number of potential family outcomes that "fit" within our Comprehensive Assessment Model.

1. **Families will have a basic understanding of child development and will be able to identify needs for their child, including those related to cultural, linguistic or disability specific issues.** A major component of ECRI-MGD is the development and measurement of Individual Growth and Development Indicators (IGDI's). The process of identifying IGDI's begins at the IEP or IFSP planning meeting when general outcomes are selected. This family outcome could be measured by observing the level of family participation in meetings over time, family self-evaluations, or family satisfaction surveys.
2. **Families will be able to assess how their child's development is progressing related to general outcomes identified on the IEP/IFSP.** As professionals implement IGDI Progress monitoring, families should participate in the monitoring process. Can family's use the IGDI measures? Can families use information from the IGDI's to monitor their child's progress? Can families use information from the Exploring Solutions Assessments to determine potential interventions? This outcome could be measured by family self-evaluation, family completion of Exploring Solutions Assessment, family active participation in intervention design, or family satisfaction measures.
3. **Families will be confident in their abilities to make choices about interventions for their child and will be able to implement those interventions effectively.** Once an IGDI has identified a problem and the Exploring Solutions Assessment has been completed, intervention

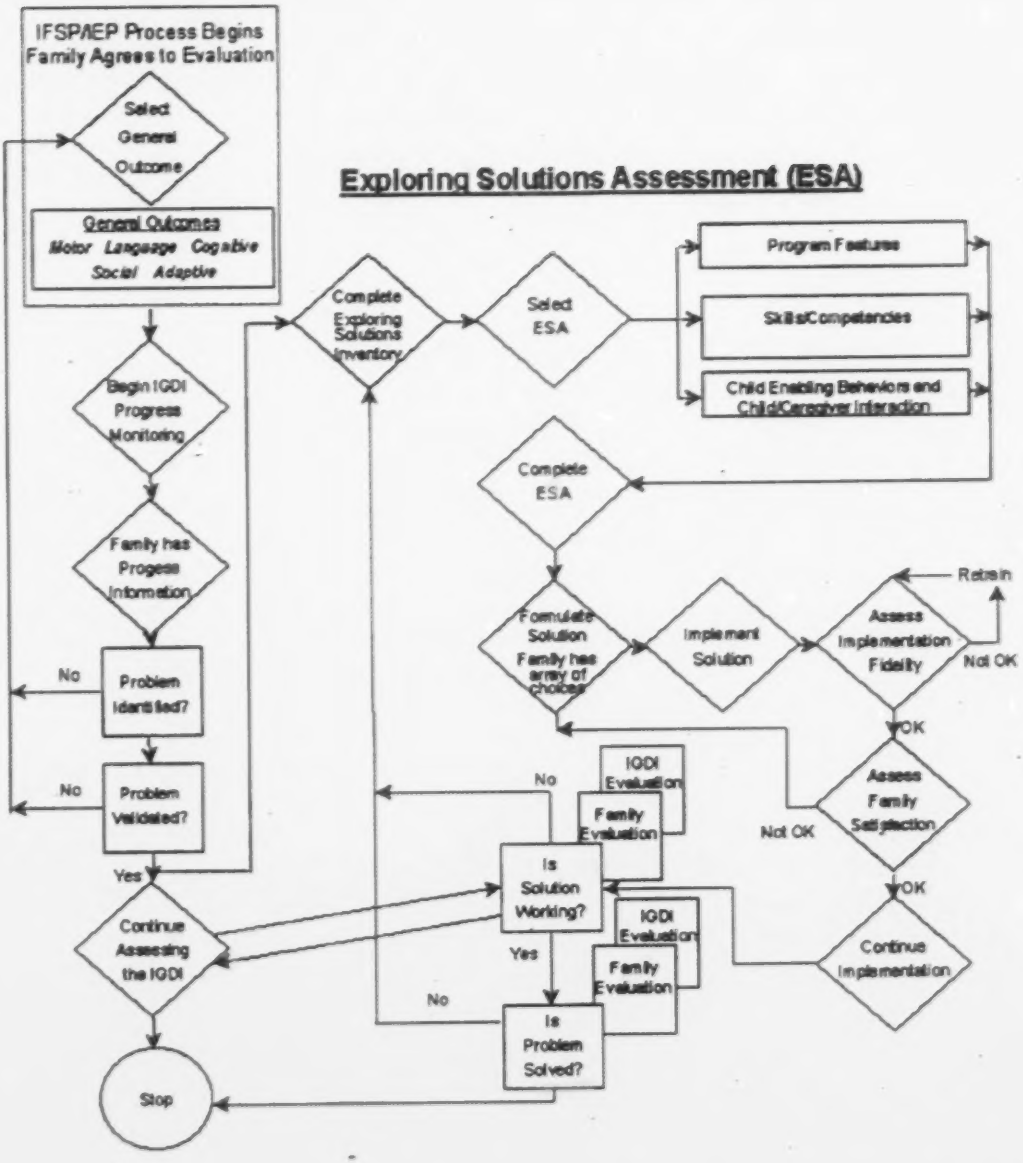
development occurs. Families should be active participants in the development and implementation of interventions. Just as it is critical that different disciplines collaborate on intervention designs in order to assure consistency it is also critical that there is consistency between the professionals and the families in implementing interventions. This does not mean that an intervention must be applied in the same way in school, home and community settings. What it does imply is that, *as a team* the professionals and family members determine the impact of the child with disabilities on the daily family routine (Bernheimer, Gallimore, & Kaufman, 1993) and what adaptations the family is willing to make to that routine in order to implement an intervention. This outcome can be assessed by observing family participation during intervention design, measuring the fidelity of intervention implementation, or family satisfaction measures.

4. **Families will feel that their beliefs and values are respected by other members of their child's team and will see themselves as equal and integral members.** Throughout our Comprehensive Assessment Model we have included families as important decision makers. In order to evaluate their active involvement, we have described three family outcomes and proposed ways to measure each of these. A final outcome relates to overall family satisfaction with the ECRI-MGD Comprehensive Assessment Model. Do families feel that they are included in meaningful and productive ways? Do families perceive that their input is sought and valued? This outcome could be measured using parent satisfaction interviews or surveys, which occur repeatedly during the course of assessment and intervention design and implementation and as the child grows and develops. For example, are families more likely to perceive themselves as an important decision maker during a child's early experiences with special education services and less important as the child grows and service delivery options change? Do families feel their beliefs and values are respected by other members of the team during initial phases of our Model (e.g. when selecting general outcomes) than during later phases (e.g. intervention implementation)?

Future Research Plans

Future research plans include validation of the 4 outcomes and selection of additional outcomes (if any). To accomplish this, PACER and ECRI-MGD investigators will conduct a validation survey of parents of children with disabilities (birth to age 8) at each of the three cooperating sites, assuring a wide selection of families from various ethnic, cultural, and linguistic backgrounds. In addition, PACER will work closely with Carl Dunst and others at Early Childhood Research Institute on Families in North Carolina and with Don Bailey and Robin McWilliam at the OERI Center at Frank Porter Graham Center at the University of North Carolina-Chapel Hill to coordinate research efforts in this important area. Finally, PACER will assist ECRI-MGD investigators in developing and validating techniques to measure family outcomes. These assessments will be part of a national field-test of the Comprehensive Assessment model.

Individual Growth & Development Indicator (IGDI)



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